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ABSTRACT

The paper describes a systematic evaluation of medical health care services for exceptional children seen at the Comprehensive Child Care Center of the Marshfield Clinic (Wisconsin) from 1975-1976 and 1976-1977. Responses to questionnaires designed specifically for parents and for case coordinators are reviewed. It is explained that parents consistently gave higher ratings of satisfaction than case coordinators. Possible reasons for this finding are considered. Implications of P.L. 94-142, The Education for All Handicapped Children Act, for the physician's involvement in planning and developing individualized education programs are discussed. A delineation of the referral pattern to the center is explained to show that more than 85% of all referrals came from non-physician based organizations. The importance of accountability by providers of health care services is stressed. (CL)

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"Medical Implications For The Education Of Exceptional Children For Implementing PL 94-142"

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INTRODUCTION

CONSUMER input into the delivery system of medical care is a prerequisite to the improvement of that care (Sommers and Nycz 1978). Evaluators of health care often recognize the need to include consumer input in an assessment of how well their services are being provided, yet fail to conduct evaluations which reflect this element (Sommers 1973). Children suspected of having exceptional educational needs* are mandated by law** to receive a free appropriate public education which includes a complete multidisciplinary team assessment to confirm exceptional needs followed by the development of a most appropriate educational program. There are a large number of exceptional children who by nature of their handicapping condition must receive medical diagnosis and/or treatment services to complete an appropriate multidisciplinary team assessment and program development procedure (Sommers, Griese et al 1978).

Palfrey, Mervis and Butler (1978) address Public Law 94-142, the Education for All Handicapped Children Act, from the point of view that a role for physicians is implied rather than defined in this law. That the physician involvement will vary somewhat from state to state, but will at a minimum involve counselling parents whose children are under evaluation. These authors interpret that the law assumes a sophistication of diagnostic ability and curriculum design that does not yet exist, and therefore places a special burden upon physicians to deal effectively with

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*Physical, crippling or orthopedic disability; developmental disability or mental retardation; emotional disturbance; hearing disability; visual disability; learning disability; or, speech or language disability.

**Both federal and state legislation mandate the delivery of appropriate services to handicapped children, i.e. PL 94-142 for Public Schools and PL 94-103 for Developmental Disability based programs (and similar state legislation throughout most of the United States).

patients now, while developing better training programs and assessment tools, and makes essential the enhancement of communication between doctors and educators. The parents of those children involved must also be part of the communication system with doctors and educators, thus forming a network of support as reported by Sommers and Nycz in 1978. Over the past few years an increasing trend in the provision of specialized pediatric care has helped to increase an awareness for exceptional children and concomitantly, more strict guidelines to help monitor this care will be a resultant effect.

A review of consumer input to modify medical practice or its' effect on health policy has been well documented by a variety of studies over the years (Lebow 1974, Lebow 1975, Lister 1976, Doyle and Ware 1977). However, there is a paucity of data reflective of how well medical services are being provided to children with exceptional health and learning needs as noted by Allen and Lelchuck in 1966. Due to increasing service and program trends for these children both in medicine and from education, a need exists to develop a system to assess how well things are going. Education has its' mandate for the provision of quality service due to legislation. Medical professionals must recognize the need to assure quality services and simultaneously develop a system making this assurance possible.

Systematic evaluation of health care services to exceptional children is lacking if not totally void. Medical services have generally been assumed by consumers to be of high quality, but this assumption has not been tested (Williamson 1971). Consumers themselves can provide a means of assessing organizational needs, goals and objectives (Sommers, Joiner et al 1970, Sommers 1973, Jones and Sommers 1975, Jones and Sommers 1976, Doyle and Ware 1977). Once the specific service expected by the

consumer has been defined in relation to services available, it is a routine task to monitor consumer satisfaction. The variance between optimum and actual consumer satisfaction can be obtained. Through an analysis of the observed variance, follow-up modification of documented weaknesses can decrease the difference between optimum and actual consumer satisfaction levels. This evaluation study is an attempt to better understand the elements associated with the provision of multispecialty medical services to exceptional children therefore improving these services.

SETTING

A longitudinal evaluation system has been implemented at the Comprehensive Child Care Center of the Marshfield Clinic. The Center began receiving referrals of children with exceptional health and/or educational needs in July, 1975. To date, the following delineation of exceptional children served by diagnosis is as illustrated below:

Diagnosis	Percent (%) Served*
Learning Disabilities and/or Dyslexia	49
Hyperactivity	42
Mental Retardation	42
Emotional-Behavioral Adjustment Reactions	32
Physical-Crippling or Orthopedic Problems	18
Hearing Impairment-Deafness	13
Seizures	11
Speech-Language Disability	10
Visual Disability-Blindness	9
Other (a number of related categories occurring in less than 10% of the cases)	

*the percent (%) totals more than 100 since a majority of children served had multiple diagnosis

Parents and case coordinators of each child referred have been asked to rate their satisfaction with medical services. Case coordinators are individuals in the child's home community who refer children for medical services or coordinate their learning and other related day activities outside the jurisdiction of the home. There has been an increased emphasis nationally and throughout the states to combine or coordinate the delivery of medical and educational services (Sommers 1978, Sommers, Griese et al 1978). The Comprehensive Child Care Center is a unit of the Marshfield Clinic and coordinates its medical services with St. Joseph's Hospital and the Marshfield Medical Foundation for children with exceptional health and educational needs. The Marshfield Clinic, the nation's sixth largest private group practice, is located in Central Wisconsin.

All medical and surgical specialties are represented in the group. There are also complete outpatient, x-ray facilities, laboratories, physiotherapy, patient counselling, and library services. Hospital facilities adjoin the Clinic in the form of St. Joseph's, a 520 bed complex. All clinic physicians have staff privileges. A non-profit Medical Foundation provides research and development opportunities. The medical service area of the clinic contains approximately two million people. Approximately 300,000 patients are seen on an annual basis with 20,000 being new for the first time. Primary care is provided to over 47,000 patients from the immediate surrounding area. Additionally, secondary and tertiary care is provided to the central and northern sections of Wisconsin. Fifty percent of the children seen through the Comprehensive Child Care Center are evaluated and treated without a need to return. These patients are referred back to their local physicians.

Referrals to the Child Care Center come from public schools, private schools, clinics, developmental disability programs, public health departments, social services, residential treatment facilities, state and federal agencies, and directly from parents. A majority of the referrals come from throughout the State of Wisconsin.

METHOD

Survey questionnaires were initially administered in the fall of 1976 to the parents and case coordinators of 130 children (89 boys and 41 girls) with exceptional health and/or educational needs who were seen at the Comprehensive Child Care Center of the Marshfield Clinic between July 1, 1975 and June 30, 1976. The next set of questionnaires was sent to the parents and case coordinators of 144 children (101 boys and 43 girls) seen between July 1, 1976 and June 30, 1977. A focus of this approach is to describe and analyze, on a longitudinal basis, the trends of rated satisfaction with medical services as perceived by the primary consumer groups having vested interests in each exceptional child. Questionnaires are sent out from the clinic on intervals of 6 months. Which means that within six months from the time the child was provided medical services, measures of satisfaction are obtained which reflect on referral procedures; scheduling problems; clearly developed and definable findings; progress being made by child; and, other important service aspects.

One questionnaire is designed specifically for parents and another for case coordinators. Three questions on each groups' questionnaire are identical and have been used to determine the discrepancy of opinion between two different observers of a similar experience. Each questionnaire is mailed, complete with a self-addressed, stamped envelope for return mailing purposes. If the first questionnaire is not returned, a second

questionnaire is sent accompanied by a letter stressing the need for the respondent's evaluation ratings and any other comments about the service. A personal telephone call soliciting the information is then made if the second questionnaire is not returned.

Each respondent (parent and case coordinator for each child evaluated) was asked to rate the questions corresponding to their level of satisfaction with the clinical service they received particularly as they related on a basic yes (positive) or no (negative) continuum. Since much essential information could not be obtained from either a yes or no response the yes-no continuum was expanded to include a rating of satisfaction scale ranging from 0 to 100 percent, with a rating of 50 being average.‡

RESULTS

Parent Survey

A comparison of parent evaluation ratings from 1975-76 to 1976-77 is illustrated in Table 1. Improved ratings are reflected in those questions dealing with clinical information provided to the parents. Regressive ratings were noted in the scheduling of appointments and in the opinion of progress made by child following medical services. The overall rating of satisfaction with services remained constant in a very positive direction.

(INSERT TABLE 1 ABOUT HERE)

The pattern of referrals finds that of the parents responding, an increased percent are coming to the clinic from over 100 miles away, as well as an increasing trend from within 20 miles. A decrease is noted among parents living between 20-100 miles of Marshfield.

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‡ Further details available on request to author.

Table 1: Parent Evaluation Ratings Comparison

Questions	July 1, 1975 – June 30, 1976		July 1, 1976 – June 30, 1977	
	Number Responding	Mean Percentage Rating of Satisfaction	Number Responding	Mean Percentage Rating of Satisfaction
1. Were you given opportunities to ask questions?	91	85	90	88
2. Was there an explanation of the medical findings as they related to the education of your child?	89	76	89	81
3. Did you receive a clearly developed explanation of all findings after your clinic visit?	89	71	86	78
4. Were your appointments scheduled properly?	91	91	89	82
5. Has progress been made since your child was seen by the Comprehensive Child Care Center?	87	70	83	68
6. Would a personal visit to your community by a member of the Comprehensive Child Care Center to follow-up on progress made by your child since the clinic visit be important to you?	85	56	74	57
7. Were you pleased with the overall service provided by the Comprehensive Child Care Center?	88	84	87	84

Case Coordinator Survey

Table 2 shows a comparison of case coordinator evaluations. Improved or constant ratings were evidenced in all questions as listed in Table 2 with the exception of the following three: Question #3. Were the medical findings helpful in determining specific educational programming activities for the child?; Question #9. Asking if it would be important for clinic staff to visit child in home community?; and, Question #13. Were you pleased with overall service? The regressive variance found in Questions #3 and #13 was 1% and 2% respectively. Question #9 is further examined in the next section as a discrepancy determination measure.

(INSERT TABLE 2 ABOUT HERE)

Distance patterns of referring case coordinators indicate that of those responding to this question, the percentage of case coordinators living over 100 miles is increasing while a decrease is noted among those living 100 miles or less from Marshfield.

Discrepancy Analysis

Significant differences between parents and case coordinators have been documented over the first two years of study on the question: WERE YOU PLEASED WITH THE OVERALL SERVICE PROVIDED BY THE COMPREHENSIVE CHILD CARE CENTER? From July 1, 1975 to June 30, 1976 a matched pair analysis yielded the following comparison statistics: $N=64$, $\bar{D}=10.63$, $s_D=28.78$, $t=2.95$, $df=63$, $p=.05$. A similar difference was observed for services provided to exceptional children seen from July 1, 1976 to June 30, 1977. A second matched pair analysis of data was completed and following are the associated statistics: $N=58$, $\bar{D}=8.88$, $s_D=32.32$, $t=2.09$, $df=57$, $p=.05$ (See Table 3).

(INSERT TABLE 3 ABOUT HERE)

Table 2: Case Coordinator Evaluation Ratings Comparison

Questions	July 1, 1975 – June 30, 1976		July 1, 1976 - July 30, 1977	
	Number Responding	Mean Percentage Rating of Satisfaction	Number Responding	Mean Percentage Rating of Satisfaction
1. Were the questions you had regarding the medical evaluation of this child answered by Comprehensive Child Care Center staff?	90	75	96	75
2. Was a distinction made between the medical and non-medical needs of the child?	89	73	96	76
3. Were the medical findings helpful in determining specific educational programming activities for the child?	88	67	93	66
4. Did the medical findings clarify your understanding of the child's exceptional educational needs?	87	68	92	70
5. Were suggestions made by Comprehensive Child Care Center staff concerning the child's educational activities appropriate to your program activities and community resources?	87	60	94	65
6. Did you assist clinic staff in the development of a plan to be used when the child returned home from clinic visit?	85	34	89	38
7. Has progress been made since child was seen by the Comprehensive Child Care Center?	87	63	92	66
8. Did you receive all necessary assistance from Comprehensive Child Care Center staff to deal with the child's exceptional educational needs?	83	62	93	67
9. Would a personal visit to your program center by a member of the Comprehensive Child Care Center to follow-up on progress made by the child since the clinic visit be important to you?	82	52	82	46
13. Were you pleased with the overall service provided by the Comprehensive Child Care Center?	88	75	93	73

Table 3: Discrepancy Check Between Parent and Case Coordinator Questionnaires

Questions	July 1, 1975 – June 30, 1976		July 1, 1976 – July 30, 1977	
	Number of Matched Pairs Responding	t - Value	Number of Matched Pairs Responding	t - Value
Has progress been made since your child was seen by the Comprehensive Child Care Center? (Question number 5 for Parents and 7 for Case Coordinators).	66	1.03 n.s.	56	–0.99 n.s.
Would a personal visit to your community by a member of the Comprehensive Child Care Center to follow-up on progress made by your child since the clinic visit be important to you? (Question number 6 for Parents and 9 for Case Coordinators).	59	–0.09 n.s.	52	1.68 n.s.
Were you pleased with the overall service provided by the Comprehensive Child Care Center? (Question number 7 for Parents and 13 for Case Coordinators).	64	2.95*	58	2.09*

n.s. = Not significant at .05
* = Significant at .05

DISCUSSION

Parents consistently gave higher ratings of satisfaction than case coordinators. This finding may be due to the personal contact associated with the experience of having a child evaluated and treated by physicians and their associated medical staff influence better ratings. Another possibility could be that parents and case coordinators want very different things from medical professionals. Due to Federal and State laws, the parent now is placed in the responsible position of approving (or disapproving) services and programs for their children. Many children with exceptional needs are referred to the clinical specialists for a variety of reasons: to confirm or rule out suspected health problems; to provide medical opinion on learning related conditions, i.e. learning disabilities, hyperactivity, minimal brain dysfunction, etc.; and, to give secondary or tertiary opinions to other professionals. Sometimes parents refer their children to medical professionals for purposes of gathering data to use against their local public school system or the community service agency.

Public Law 94-142 mandates complete appropriate programs and services for children with exceptional health and/or educational needs. Although a role for physicians in this act is implied rather than defined, the number of children receiving medical services will continue to increase for two basic reasons: (1) more medical training programs and educational opportunities for the pediatric specialties (i.e. pediatric neurology, pediatric cardiology, developmental pediatrician, etc.). This specialized emphasis has been most meaningful for those children with problems of both a medical and educational nature. (2) medical professionals are more frequently being involved as team members (officially or in ex officio

capacities) in the planning and developing of Individualized Education Plans (I.E.P.'s) pursuant to PL 94-142. This interest will encourage more referrals to medical organizations.

More than 85% of all referrals to the Comprehensive Child Care Center are from non-physician based organizations. Following is a delineation of the referral pattern:

Referral Source	% of Total Referrals
Physicians	13.77
County and State Agencies	13.76
Private Agencies	16.31
Self	6.16
Public Schools	50.00
	100.00%

Given this situation, it is incumbent upon the providers of health care services to demonstrate accountability for their services by assessing the impact between and among all of those consumers for which the services have been developed to serve. The evaluation procedure discussed within this study assesses consumer satisfaction on a semi-annual cycle. By focusing on specific service elements over time, it is possible to align optimum versus actual consumer satisfaction. By focusing on each documented weakness of the delivery system, modification of observed weaknesses can decrease the difference between optimum and actual consumer expectation levels leading to an assurance of the most efficient level of service.

SUMMARY

A study of consumer satisfaction with medical services provided to exceptional children was the focus of this study. The Comprehensive

Child Care Center of the Marshfield Clinic has been providing multi-specialty clinical service to children with exceptional health and/or educational needs over the past three years. The medical services provided have been assumed to be most appropriate, however, this assumption has not been tested. PL 94-142, The Education For All Handicapped Children's Act of 1975, mandates that public schools provide optimum learning related experiences to each exceptional child and implies that physicians account for their care to the same children.

An attempt has been made to evaluate how well medical services are being provided and whether significant differences exist between two different consumer groups (child's parents and case coordinator) who have been asked to rate the same service. Results indicate that parents and case coordinators are significantly different ($p=.05$) in their overall rating of satisfaction with the same service. This significantly different finding has occurred over the first two formal periods of consumer evaluation in an on-going cycle of medical service assessment.

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